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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled:

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*Advance Directives: Accessibility and usability*

*The role of information design in the development  
of a critical-use document*





## Abstract

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This paper approaches the design of forms and specifically Advance Directives, from a conversational model. Forms are not static documents. They are a means for a dialogue between the form-filler and the distributor as well as the administrator of the form.

An Advance Directive is a document containing a person's instructions about healthcare decisions including life-sustaining treatment, should he or she become incapable of making his or her instructions known. Unlike other forms and questionnaires, Advance Directives are highly individualised. Although general design principles can be applied, the information to be discussed is basically of an emotional nature, and therefore the response to the information varies from case to case.

Relevant literature has been reviewed and interpreted, experts have been interviewed and tests with subjects that represent the core user group have been conducted in order to develop the document. Information design research specifically based on emotional responses to forms is limited. The majority of research previously conducted regarding the design of forms was collected in relationship to business and government forms. Based on the analysis of existing Advance Directive forms and discussions with legal, medical and potential users, an Advance Directive Package was developed which includes an Advance Directive form as well as a booklet containing Advance Directive decision-making information.

Although information designers are not responsible for the writing of the text, they have a responsibility to develop information documents which are understandable to the users. Part of this responsibility includes addressing issues of content.

The objective of the Advance Directive Package is to initiate discussions between the person wishing to complete an Advance Directive form and those close to them. Test subjects responded positively to the package. The subjects found the information accessible and understandable, and they felt encouraged to discuss the information presented in the package with their family and friends. Minor changes were made to the package after the interviews with subjects were completed. From an information design standpoint, further research should be conducted regarding the use of colour, example pages and tick boxes in the Advance Directive Package.





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## Background

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### Introduction

*“Communication first appeared in its modern usage in the fifteenth century as an action ‘to make common to many’. By the end of the fifteenth century ‘communication’ had become a noun - the ‘object thus made common’. However, from the late seventeenth century a new sense emerged which extended its use to cover the **means** of communication. In this more modern sense it was often used as a generalised way of referring to transport systems, particularly during the main period of development of roads, canals and railways. In the twentieth century it has come to refer more to the means of conveying information and ideas rather than goods and people; **transmission** has been emphasised in this usage.” (Sless 1986: 11)*

Everyday we are bombarded by information that influences us in one way or another. This information barrage comes via various media including advertisements in newspapers, signage in subway stations, e-mail on computers, instructions on medicine bottles, warnings on household cleaners and forms in insurance offices. When the information is important to a person's health, safety and well-being, it is imperative that it be developed and designed for optimum clarity and understanding.

“Critical-use” documents are information documents which address concerns of health, safety and well-being. They may be used in emergency situations, in dangerous environments and with hazardous products. When critical-use documents are being used, those employing the documents may find



themselves under considerable stress and anxiety. Warning labels, fire escape instructions, Advance Directives, safety guidelines and medication instructions are some examples of critical-use documents.

“Failure to understand or carry out instructions can have serious adverse consequences. Machines operated incorrectly may be unsafe ... The quality of life may be unnecessarily reduced if help and support which is available goes unclaimed. Medicines and nutritional products which are misused may damage the consumer's health.” (Wright 1994: 1.2)

## How can design facilitate the accessibility and usability of information?

*“Just as there is a need for the physical working environment being ergonomically tailored to fit the man on the job, so there is a need for the cognitive demands of written information being ergonomically compatible with the psychological process of comprehension.” (Barnard 1979: 209)*

According to Gray, “[The] contribution [of the designer], in layout and presentation, is often the first thing to register on the eye of the recipient. [The] role [of the designer] as part of the team is to bridge the communication gap between the author ... and the persons” receiving the information. (Gray 1975: 85) Designers should be consulted when information documents are developed, at the beginning of the process, before all decisions about content and format have been made.





Designers can identify problems with existing information documents. Information designers working with experts in other fields can develop problem-solving approaches in order to make information more accessible and usable. This is especially important when considering critical-use documents, such as Advance Directives, where cognitive and emotional factors may influence the decision-making of the user of the document.

In developing such a document, a designer is concerned with how to communicate to and with people about their own potential serious illness or death, and with creating a dialogue between the person who wishes to complete an Advance Directive and his or her caregivers. The emphasis is not so much on visual innovation, but rather on effectiveness. From the point of view of visual communications, the designer must facilitate the clarity of the information by discussing the requirements and concerns with all the users of the form. The result should be a document whose effectiveness is centred on the accessibility, clarity and usability of the information it contains.

Most people think about death in the abstract, as something that is distant and inconceivable, which happens to others but not themselves. Communicating information of this nature involves unique concerns related to the user's response, particularly stress and anxiety that results when one considers or discusses one's own possible illness or death. Context can play an important role.

The way the information is presented, where it is presented, who presents it and when it is presented can affect the form-filler's comprehension of the information. The manner in which the information is presented can reduce stress and anxiety by providing information when and where the form-filler needs it.

Although making decisions about life-sustaining treatments is highly personalized, appropriate decisions can only be



made if adequate information is provided. It is not enough, however, to simply provide the necessary information. The information must be communicated, whether visually or verbally, in a manner by which the receiver of the information is able to clearly understand, and thereby make informed decisions.

## Communication models

There are a number of ways of thinking of 'communication'. As mentioned previously in a quotation by David Sless, in the twentieth century, communication has come to be thought of as a transmission of information and ideas. One common model of communication is that of a sender and a receiver.

**FIGURE 1**



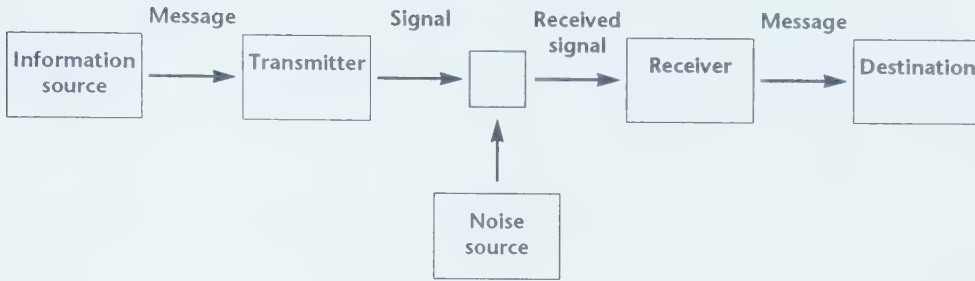
In this model, someone has information (sender) which they wish to convey to another person (receiver). It is a one way transmission of information. In this model there is no assumption of a dialogue between the sender and the receiver.

Figure 2 presents another model of human communication which is based on a mathematical theory of communication. (Sless 1986: 13, 14) In this model a sender (information source) and a receiver are also incorporated, but other factors are considered. The medium of the message (transmitter) affects the way the message is received. Outside interference (noise source) also affects the message the receiver acquires. This model encompasses a destination for the information which is determined by the receiver, but the transmission of the information is linear and not interactive.





**FIGURE 2** Model adapted from Sless 1986: 13



This paper approaches communication as an interactive and not linear process. Communication is defined as a sharing of information between the source of the information and the interpreter of the information. The perception of the communication by the interpreter is dependent upon many factors, including the manner in which the information is presented and the relevance of the information to the interpreter's needs. The process of communication is not seen in isolation, but rather in a given context at a given time.

**FIGURE 3**



## Information design

Some designers would say that information design is a specialisation within graphic design. Those who agree with this definition, believe that information design includes the aesthetic and promotional aspects of graphic design, but that it also addresses the cognitive functions of information, including perception.

*“A necessary condition for good graphics is its appearance; a necessary condition of good information design is its **performance**.” (Sless 1994: 12)*



Other designers would say that information design precedes the production of visual presentations and defines the content of a message and the way in which elements of the content relate to one another. Before the actual design of the information occurs, considerable research is conducted regarding the needs of the user of the information. What the user should be told, what the user needs to know and how the content should be organised, are some of the concerns which are addressed prior to the actual design of the information. The aesthetic and promotional aspects often associated with graphic design are also considered in this definition, but the emphasis of the design process is to assist the user. Many people may be involved in the design of information, not only designers but also behavioural psychologists, for example. "One fundamental aim of behavioural research is to understand how people process information." (Wright 1981A: 157)

According to David Sless from the Communication Research Institute of Australia, information design is concerned with "solving practical problems within and through a specific cultural and historical context" (Sless 1994: 12) and it "is about managing the relationship between people and information so that the information is accessible and usable by people." (Sless 1994: 1) Information design goes beyond the aesthetic and promotional concerns often associated with graphic design, and addresses concerns which deal with the health, safety and well-being of the user of information documents, including critical-use documents.

This thesis approaches information design as an interdisciplinary process which defines the content of the message and the way in which elements of the content relate to one another, before the production of information documents begins. Criteria regarding effectiveness of visual presentation and comprehension of information are considered as part of the information design process. The designer works together with experts in other fields to develop an information document which is accessible and understandable by the intended user.





## Designers and researchers

Information designers generally attempt to approach the design process from an interdisciplinary perspective. Researchers may be consulted from fields such as cognitive psychology, ergonomics, linguistics, educational psychology and computer science. However, working together or incorporating research from fields other than design can be difficult at times.

For example, following are some of issues identified by Dr. Patricia Wright of the Applied Psychology Unit of the Medical Research Council at Cambridge, regarding cooperation between psychologists and designers:

- “There are no simple remedies for the problem of information designers not fully understanding how their readers behave. Several difficulties face those who try reading the relevant journals. An on-line search can be frustrating because the key words that seem most relevant [to the information designer] ... have other dominant meanings in the research literature ... Even when references have been found, the papers will be scattered through a wide variety of different journals. Few libraries take them all. Once a relevant paper is obtained there remains a translation problem. The domain content, the readers studied, [and] the reading situation will all differ from those facing the designer ... A design solution that works well in one context may not be the best solution in another, even when the domain and the audience remain the same (Wright and Reid, 1973).” (Wright 1994: 1.5)
- “Cognitive psychologists have their own agenda. Their priority is to understand the mechanisms of intellectual behaviour. The scientists represent their understanding in the form of models but each model will address only a small subset of cognitive processes.” (Wright 1994:1.6)
- “Guidelines [related to how people read] appear to provide research findings in an easily assimilated form, but they have many limitations. Designers need to know the risks from contravening the guidance. If the print is smaller



than that recommended will people just be slower, or will they bring their eyes too close to danger zones trying to read the warning that says to not get too close, or will many people be prevented from accessing the material at all?” (Wright 1994: 1.6)

- “[I]t can be more useful for information designers to know what to avoid than to know what to do. Compromise is safe as long as the catastrophes are avoided, catastrophes such as search failures, misunderstandings, or faulty action plans.” (Wright 1994: 1.12)
- “Because psychologists are interested in cognitive processes, not in design options, little has come from the opportunities for dialogue between the design and research communities during the past decade ... It is suggested that the remedy may require that both designers and researchers find the dialogue mutually beneficial.” (Wright 1994: 1.1)

## Form design

*“A form appears to be a special kind of communication medium for conducting a written conversation. It is a method of communicating in visible rather than verbal language.” (Frohlich 1985 cited in Barnett 1988: 5)*

One area of information design which consistently causes problems for its users is the design of forms. Poorly designed forms may cause undue stress and anxiety for the form-filler. One example of such a form which must be completed by a large percentage of the population is an income tax form. Whether they entered their first name in the wrong space, or simply did not understand what information they were required to provide, most people have at one time or another had difficulty completing a form.

Human communication, whether visual or verbal, is governed by rules which are both formal and informal. These rules can be “specific to a particular culture, ethnic group, organisation, or just among one’s peers.” (Barnett 1989B: 1)





Although forms can incorporate some of the same design principles used for other types of information design, they also have their own inherent design problems and rules. Forms incorporate a variety of conventions such as tick boxes, ‘for office use only’ areas, crossing out whatever does not apply, circling what does apply, and writing N/A in areas which are not applicable.

The following example is taken from the 1995 University of Alberta application for admission form. The section of the form represented here is shown at actual size. Text on forms is often set in small point sizes to accommodate all the information that must be presented and collected. Although this form is legible, those individuals with vision problems may have difficulty reading the type. Some form conventions shown in this example include delimiters (the character separators for date and Social Insurance Number requests), tick boxes (boxes to mark the applicable option) and two part questions (if you answered yes, please answer the following question).

FIGURE 4

Surname		
First Name and Middle Name(s)		
Former Name (if applicable)		
Date of Birth year month day	<input type="checkbox"/> Male <input type="checkbox"/> Female	Canadian Social Insurance Number
Place of Birth (country, city)		
Country of Citizenship		First Language

State the number of full-time years of formal education you have had where the language of instruction was English. Count all years, from Grade 7 (or equivalent) through postsecondary.

\_\_\_\_\_ year(s)

Will you have been a continuous resident of Alberta, the Yukon, or the Northwest Territories for at least one year prior to your intended date of attendance at the University of Alberta?

☐ Yes ☐ No

If yes, give year and month you became a resident of Alberta, the Yukon, or the Northwest Territories, even if it is your birthdate.

year month

\_\_\_\_\_

---

**Aboriginal Applicants**

If you wish to declare that you are of aboriginal ancestry within the meaning of the Constitution Act of 1982, indicate:

☐ Status Indian ☐ Non-status Indian ☐ Bill C-31 ☐ Métis ☐ Inuit

Have you attended the Transition Year Program (TYP) for aboriginal students at this University?

☐ Yes ☐ No



“In form design the most important and frequent reason for failure is the inability of designers to see forms from the user’s point of view.” (Grant et al, 1982 cited in Barnett 1989B: 15)

Unlike many examples of information design, forms generally involve several users, a minimum being the distributor, the form-filler and the administrator. A more extensive list could include: a receptionist, a data analyst, a researcher, a data processor, a review committee, an accountant and a legal advisor. A request for a senior citizen’s benefit, for example, could be used by the person requesting the benefit, reviewed by an administrator, confirmed by a researcher, entered into a computer system by a data processor, processed in the finance department by a clerk, and filed by an administrative assistant.

Each user of a form has different requirements of the document. “There are problems concerning the interrelations among questions, the perceptual flow down the page and the compatibility between the ordering of the items on the page and the conceptual organization of relevant knowledge in the heads of both the form-fillers and the administrators.” (Wright 1981A: 152)

There is a lack of awareness of the importance of forms and form design. “The misconception is that forms are only pieces of paper with spaces for filling in information.” (Barnett 1988: 5) Working on forms is often considered “boring and unattractive, and certainly ... less intellectually demanding than other work done by administrative group staff.” (Barnett 1988: 5) A British government study conducted in 1982 found that officials at all levels of administration often viewed forms “as unimportant and trivial.” (Barnett 1988: 5)





Often users approach forms with preconceived ideas. It has been found that many people do not read instructions, even when they are short. (Wright 1981A, Barnett 1989B) Forms, therefore, must be designed to motivate the form-filler to complete them in the appropriate manner.

Standard readability formulas, which measure comprehension levels of text, generally cannot be applied to forms because these formulas were developed for prose, and forms usually do not have large areas of continuous text. Delimiters, which are marks, boxes or lines that divide character spaces, have continued to be used on forms, although they have been found to hamper performance of both the form-filler and data processor.

There are many different ways that questions can be asked. Forms are often complex in format and content. They can incorporate a number of question presentation styles, including matrices, open-ended responses, yes/no responses and multiple choice responses.

“The fundamental cause of bad forms more probably lies in a failure to appreciate the range of skills required for achieving a satisfactory design in which so many conflicting interests have to be reconciled.” (Wright 1981A: 6) This is especially important to consider when developing forms where a number of different interests must be addressed, such as Advance Healthcare Directives, where emotional, medical and legal requirements have to be considered.



## What is an Advance Healthcare Directive?

*“Throughout life, people are used to making decisions for themselves, but when they are diagnosed as having a life-threatening illness, they are suddenly transported, with their families and friends, into a totally foreign environment ... There they must listen to various professionals and specialists who speak a foreign language called medicalese. As patients, they must acquiesce to taking a series of uncomfortable and scary tests. Without notice, they must be prepared to make drastic changes in their schedule, lifestyle, and commitments. Finally, the doctors expect them to make decisions and choices that, in the truest sense, deal with life and death.” (Burnell 1993: 100-1)*

An Advance Healthcare Directive is a critical-use document containing a person's instructions about healthcare decisions, including life-sustaining treatment, should he or she become incapable of making his or her instructions known. An Advance Healthcare Directive also may be called an Advance Directive, an Advance Medical Directive, a Healthcare Directive or a Power of Attorney for Personal Care. Advance Directives are often called Living Wills, but unlike Last Wills, they take effect before death.

The expression “Living Will” was first used by Luis Kutner, an attorney, in the 1930s. “Bishop Fulton Sheen was the first person officially to execute Kutner's ‘testament permitting death’ without heroic medical treatments; actor Errol Flynn was the second.” (Williams 1986: 7)

A person may make an Advance Healthcare Directive (which will be referred to as an Advance Directive in the remainder of this paper) if he or she is able to understand treatment





choices and appreciate their consequences. An Advance Directive only takes effect when the individual can no longer understand and appreciate treatment choices.

More and more medical professionals, institutions and associations are developing Advance Directive forms.

“The debate over the freedom to choose and the patient’s ability to retain control is taking place in various circles of experts in ethics, medicine, law, philosophy, theology, and public policy.” (Burnell 1993: 97)

## **Informed consent and decision-making**

*“Generally speaking, any individual who is able to understand the nature and anticipated effect of proposed treatment and the alternatives, including the consequences of no treatment, is competent to give valid consent.” (Evans 1990: 228)*

When receiving medical treatment, the patient must consent to the treatment or treatments unless informed consent cannot be acquired because of a medical emergency.

In Canada, physicians must provide their patients with information about proposed treatments or procedures, their seriousness, any significant risks, and any alternatives to the procedure. “The adequacy of consent explanations are now to be judged by the ‘reasonable patient’ standard, which is what a reasonable person in the particular patient’s position would have expected to hear before consenting.” (Evans 1990: 229)

Context can play an important role in the decision-making process. Timing, location and who obtains the informed consent are some of the factors to consider with regard to the subject’s ability to comprehend the information provided.



“[A] patient’s decisional capacity could be facilitated (or inhibited) by the manner in which the information was conveyed or by the circumstances under which the information was presented. ... contextual psychological perspectives suggest that informed consent doctrine should view decisionmaking as an ongoing process and should recognize the importance of individual characteristics of patients, the relevance of environmental influence, and the reversibility of apparent defects in the decisionmaking process.” (Altman 1992: 1682)

A consent form serves a different purpose from a request form. “The data is not used to compile statistics but simply as a written verification that a dialogue about medical treatment/procedures has occurred between a patient and their medical caregiver.” (Altman 1992: 1701)

Advance Directives are in a sense a type of medical consent form. Instead of being requested by a medical professional, however, the form-filler usually initiates the dialogue. The individual completing an Advance Directive must be competent to make decisions about future healthcare and is therefore consenting to future healthcare.



## Advance Directive issues

*“Useful guidelines on writing well have been available for more than fifty years (e.g. Fowler, 1926). Yet many legal documents are a lexical steeplechase, in which intrepid readers surmount the hurdles of archaic terms only to stumble at the lengthy waterjumps of qualifying clauses packed end to end against each other. Such language inevitably restricts people’s access to information.” (Wright 1980C: 121)*

The legal community has recently made a conscious effort to clarify the language used on legal documents. “Plain language” has become a positive issue being addressed by legal professionals. Information designers have always encouraged the use of clear information, whether it is textual or visual.

The following reproduction of the text of the State of Alabama Declaration is an example of information which is not presented in a clear manner.

“I, ... (Name), being of sound mind, willfully and voluntarily make known my desires that my dying shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures





would only serve to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care.” (Williams 1986: Appendix A)

Examples such as the State of Alabama Declaration are to be avoided. Language should be presented in a clear and understandable manner. (Wright 1980C: 121) Clear and understandable does not necessarily mean short in length. Unlike the State of Alabama Declaration, the points to be addressed should be expressed in a number of sentences, rather than one extended sentence.

There is currently no legislation in Alberta specific to Advance Directives. Bill 58: Advance Directives Act, however, has been proposed. This Bill would make Advance Directives legally binding in Alberta if it is medically and legally within the power of the healthcare provider to fulfill the directives made by the patient. The legislation is expected to come into force in 1995.

In 1993, a joint report of the Alberta Law Reform Institute and the Health Law Institute was published entitled “Advance Directives and Substitute Decision-making in Personal Healthcare.” This report was the result of research conducted over an extensive period with members of the medical and legal communities as well as the general public. The research conducted was concerned with the current status of Advance Directives in Alberta, and the conclusions provide proposals for draft legislation. “The intention of the proposed scheme is to create advance directives which are relatively simple to create, which will provide clear and unambiguous instruction to the healthcare decision-maker and will settle issues without resort to delaying litigation.” (Alberta Law Reform Institute 1993: 2)



Among the points addressed in the report were:

- “We [The Alberta Law Reform Institute and The Health Law Institute] anticipate that many healthcare directives will be drawn up without legal advice.” (Alberta Law Reform Institute 1993: 16)
- “to include a recommended form in the legislation might well give the misleading impression that it is the only form (or the preferred form) of healthcare directive, and thus might be adopted regardless of the particular individual’s needs and circumstances. A healthcare directive should be tailored to fit the wishes and needs of the individual, and we [The Alberta Law Reform Institute and The Health Law Institute] would not wish the legislation to imply that there is a ‘boilerplate’ version which can be used in all cases.” (Alberta Law Reform Institute 1993: 17)
- “Our [The Alberta Law Reform Institute and The Health Law Institute] final recommendation was that appropriate education programs be established to ensure that the general public, and healthcare professions and institutions, are made fully aware of the legislation governing healthcare directives and proxy decision-making.” (Alberta Law Reform Institute 1993: 31)

Not all Advance Directives will be completed with the assistance of a lawyer or a physician. The need for better education programs about Advance Directives for those outside the legal and medical professions is therefore imperative.

*“Over the last fifty years medicine has advanced at an amazing pace. What would have been considered miraculous fifty years ago is now routine. People are kept alive with heart, kidney and liver transplants. Arms are sewn back on, and cancers that were once fatal are cured. At the same time modern medicine has become complicated, more technological and more sophisticated.” (Molloy and Mephram 1992: 1)*





Individuals who wish to complete Advance Directives should be encouraged to discuss their wishes with those close to them as well as with their healthcare providers. Because of the technological advances, however, it is important that these individual's discuss possible life-sustaining treatments with their healthcare providers.

In a study conducted in Ontario by Hughes and Singer in 1992, 86% of participating physicians said they were in favour of Advance Directives, while 3% were against them and 11% were undecided about their use. According to this study, there is a concern in the medical community, however, whether or not the physician should introduce the topic of Advance Directives or wait for the patient to address the issue (Hughes and Singer 1992: 1943). Of those physicians who participated in the study, few had discussed Advance Directives with their patients. In a presentation given by Dr. Singer in Edmonton, he suggested that who should initiate the dialogue depends on the individual patient. As the patient becomes more ill, however, the onus should be on the doctor to raise the subject.

Another concern is the distribution of information within the medical community itself. In a presentation about Advance Directives given by Dr. Singer at the Misericordia Hospital in Edmonton on May 3, 1994, he asked how many of the people in the audience (mainly composed of physicians) had seen The University of Toronto Centre for Bioethics Living Will? Two or three of the approximately 40 people in the room raised their hands. Then Dr. Singer stated that the University of Toronto Centre for Bioethics Living Will was distributed to every English speaking physician in Canada, implying that the majority of those present would have received a copy of the Living Will.

Terms that have specific meanings from a medical standpoint, may be subject to different interpretations by people outside the medical community. Phrases such as "heroic efforts" or a patient being in a "persistent vegetative state" may be found on Advance Directives currently in use.



“Many people are ... confused by the jargon that health professionals use. A person can go into hospital and have an ECG, EEG, EMG, colonoscopy, laparoscopy, bronchoscopy, or a hundred other tests for diseases such as SLE, COPD, or IHD. For the person with the disease this jargon is meaningless. The patient experiences pain, shortness of breath, weight loss or tiredness. Blood tests and x-rays mean needles and scans that create endless printouts and images on screens.” (Molloy and Mepham 1992: 2)

Phrases such as “do not resuscitate” (DNR) and “no code” orders are familiar to healthcare professionals, but not necessarily to their patients. When patients have expressed their desire not to be resuscitated if they require life-sustaining treatments such as cardiopulmonary resuscitation, a DNR or no code order may be added to the patient’s file. This type of instruction is just one example of an Advance Directive.

## Design rationale

*“Design decisions often involve compromise, guidelines give no indication of how to make such compromises.”*  
(Wright 1981A: 155)

Why choose to research Advance Directives from a design perspective? Unlike other forms and questionnaires, Advance Directives are highly individualised, and although general design principles can be applied, the basic information to be communicated is of an emotional nature. Form design research based on emotional responses to printed information is limited.



Many of the existing Advance Directives have tried to address the content of the form, but do so either from a legal or a medical perspective, and do not provide the information that individuals may require to make informed decisions. The language used on existing forms is often complex or, as stated previously, terms such as “persistent vegetative state” or “heroic measures” are used which may have different meanings for each person.

Although information designers are not responsible for the writing of the text, they have a responsibility to develop information documents which are understandable to information users. Part of this responsibility includes addressing issues of content. By working together with professionals in law, medicine and ethics, as well as the users of the form, a new Advance Directive document may be designed which addresses the concerns of the form-filler in a sensitive and informative manner.

The research conducted for this thesis about form design and Advance Directives has resulted in the production of an Advance Directive Package which is intended to facilitate a dialogue. This dialogue is not only between the form-filler and the information presented, but also could be between the form-filler and his or her family, healthcare proxy, healthcare providers, as well as friends, lawyer and spiritual advisor.

The design of this Advance Directive Package has been approached from an interdisciplinary perspective. Although the research conducted approaches the design of these forms from an Alberta perspective, the final product could be a helpful precedent for legal and healthcare professionals, and more importantly, is understandable to the users.

Clarity of language is one concern which is addressed, but to determine appropriateness of the design, the use of colour, type size and graphics have also been considered. Relevant





literature has been reviewed and interpreted, experts have been interviewed and tests with subjects that represent the core user group have been conducted in order to develop the design document.

The work which was undertaken before the design itself began is extensively documented in this thesis. Although the research findings relate to a specific document in a specific context, the findings are described, so that these findings may be consulted when designers are approaching other design problems.



## Research review

### Advance Directives

Through searching medical, legal and psychological sources, it appears that the majority of the research relates to informed consent, plain language and legislation. Besides “Consent to medical treatment: The use of consent forms” (Hearn 1992), there is little research on what to include on an Advance Directive.

Both legal and medical sources consulted were concerned with defining and acquiring informed consent. This may be due in part to the fact that many of the sources searched were American, where large monetary lawsuits against physicians and medical institutions are more prevalent than they are in Canada. This is not to say, however, that legal suits of this nature do not occur in Canada. The research of legal and medical literature also included information about specific court cases related to informed consent, Advance Directives, and decision-making for incompetent patients (Crowley 1992, Margolis 1992).

The psychological sources searched often dealt with readability of informed consent material (Handelsman, Mitchell and Martin 1992), but these studies were usually performed on text presented in a prose format and not in point form. Psychological research has also been conducted with specific groups attempting to determine why individuals act or react in certain ways to Advance Directives (Henderson 1990, High 1992).

Within the medical and psychological literature were several sources about death and dying (Kübler-Ross 1969, Callahan 1987, Brock 1993, Burnell 1993, Seguin 1994). These medical and psychological sources included discussions on the stages of dying, the legal and moral implications of euthanasia, and the decision-making process as an interactive dialogue between patient and healthcare providers.



As well as researching the relevant legal, medical and psychological literature, existing Advance Directive forms were reviewed. These forms were Canadian, American and British, and were produced by medical, legal and government sources as well as organisations such as the Society for the Right to Die and Dying with Dignity.

Along with researching form design, Living Wills, Advance Directives, informed consent, and general design concerns in traditional academic sources (journals, annuals, and books), other sources were also reviewed. Television and newspapers provide verbal and visual presentations of information both to promote (advertisements) or to inform (documentaries and articles).

In 1993 ITV News in Edmonton presented a series about Advance Directives on its evening news. There are often articles about Advance Directives and Living Wills in such publications as “Today’s Maturity”, “Good Times” and “Senior’s News.”

Although there are currently no television advertisements about Advance Directives, there are commercials related to insurance, medical care and funerals which deal with emotional subject matter.

More attention is also being drawn to the question of euthanasia within Canadian society due to some recent legal cases. Local newscasts, as well as newspapers have presented a number of articles related to the Sue Rodriguez and Robert Latimer cases. The Edmonton Journal has published many letters to the editor both for and against euthanasia as a result of the publicity of these cases.

“Euthanasia” literally means a good death and for this reason is often used interchangeably with “Living Will” in the media. Although many people are still unaware of Advance Directives (sometimes referred to as Living Wills), the





public's awareness of euthanasia is increasing. Euthanasia is generally understood as an act with the intention of provoking a "good death" and to advance death. Euthanasia, however, is illegal in Canada.

### **Information design**

The majority of the design research consulted regarding form design, was from a business or government perspective (Vardaman 1971, United Kingdom, Civil Services 1972, United Kingdom, Inland Revenue 1984, Barnett 1984, United Kingdom, Cabinet Office 1985), and emotional factors were not considered. Within this context, however, research has been conducted that relates to the overall composition of a form. Such studies include research about the legibility of print (Gray 1975, Forms Information Centre 1984B), the viability of delimiters (Wing 1979, Barnett 1984, Forms Information Centre 1989A) and the usability of colour (Waller 1982, Forms Information Centre 1986A, Barnett 1989C).

Some general design suggestions have been made which are based on research conducted in applied psychology on forms (Wright 1975) and language and question style used on forms and questionnaires (Wright 1973, Barnard 1979, Forms Information Centre 1985B). Design studies also have researched the processing of information (MacDonald-Ross and Waller 1975, Schumacher 1981, Wright 1981A, Tufte 1990). Considerable research has been conducted with regards to legibility (Tinker 1963, Spencer 1969) which includes typographic coding (Spencer 1973A, Spencer 1973B, Spencer 1974).

In addition to reviewing the relevant information design literature, correspondence and consultation with experts in the fields of form design, information design and cognitive psychology were conducted. Ms. Mary Dysan, Mr. Paul Stiff, and Dr. Michael Twyman of the Department of Typography



& Graphic Communication at University of Reading; Dr. Patricia Wright of the MRC Applied Psychology Unit at the University of Cambridge, and Mr. David Sless of the Communication Research Institute of Australia were each consulted about their own research as well as suggestions they had with regards to approaching the design of Advance Directives.



### General form design considerations

*“The extent to which the ... designer can create a manifest form that, while accomplishing its purpose as a support for the user’s task in filling it, still retreats to the background by putting the user’s entries into the visible foreground, will have made a contribution to human dignity and the worthwhileness of human efforts.” (Barnett 1989B: 6)*

After answering a question, form-fillers move to the place on the page where they expect the next question to be. Consistency is important. The visual cues that are given at the beginning of the form will influence how the reader moves through the form. In “Forms for the general public: do they really work?” Robert Barnett from the Communication Research Institute of Australia suggests that:

“A cluttered appearance on the first page creates negative attitudes – but so do large numbers of pages. Negative attitudes caused by the latter can be minimised by making progress through the form relatively easy. A well designed form causes people to gain confidence and a more positive attitude as they progress.” (Barnett 1989A: 13)

Effective design can make a form appear professional, which can increase the perceived importance of the form to the user. Form-fillers can become frustrated when there is not enough room to provide answers, when a question is unclear, when they do not know where to place their answer, or when they do not know how precisely to answer a question. “Staff who edit forms and phone form fillers to check answers are one of





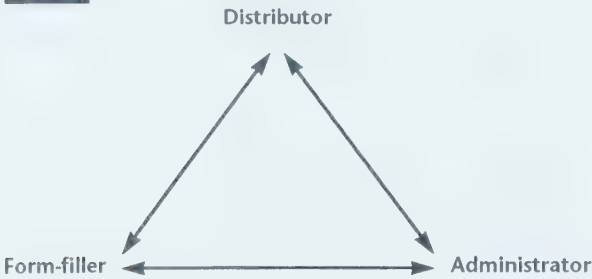
the best internal sources of qualitative information about the failure of a form or the nature of form fillers.” (Barnett 1989B: 23) These members of staff can make an important contribution to the designer’s understanding of the way the form is used.

Forms are not static documents. Forms are a medium for asking questions and giving answers.

“It is useful to think of forms as mediating between two groups: the people who fill them out, and the people who read and act on them.” (Charney 1984: 131)

They are the evidence of a dialogue between the author of the form (distributor), the person who completes the form (form-filler) and the person who acts on the completed form (administrator). The form-filler may also have an advisor who assists them in completing the form. In many cases the person or organisation who is the distributor may also be the administrator of the form.

**FIGURE 5**

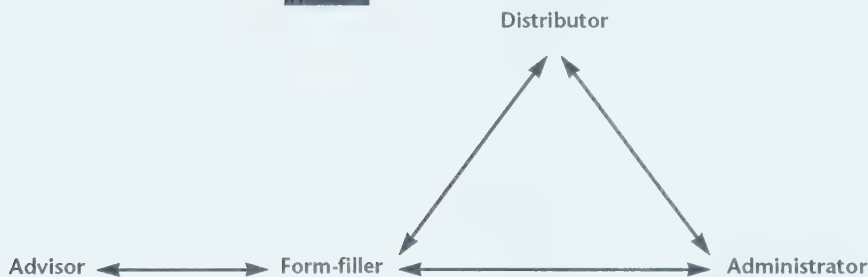


The distributor sets the general context for the distribution of the information. The form-filler completes the document based on what they believe the distributor is asking for, and what the administrator is looking for when the form is processed. The administrator acts on the information provided by the form-filler within the context established by the distributor.



In the case of Advance Directives, the form-filler often may be considered the distributor, because they are usually setting the context for, and defining the content of the document. The person who completes an Advance Directive may have assistance from someone such as their spiritual advisor, their doctor or their lawyer who could be acting as the distributor of the form, or simply as an advisor to the form-filler. When the Advance Directive comes into effect, the advisor may not have any part in the specific decisions being made. The doctor, healthcare providers, healthcare proxy and family members who act on the instructions in the Advance Directive are the administrators in this dialogue.

**FIGURE 6**



Considerable design related research has been conducted on forms. The topics studied have included question style, colour use, typographic coding, graphic coding, information sequencing and computer data input.

This information was generally collected in relationship to business and government forms. The studies consulted do not generally deal with information of an emotional nature, but rather of a cognitive nature. Having said this, the basic form design considerations are still relevant to the design of Advance Directives.

It is imperative that the questions to be asked on a form are effective before implementing the design. If the questions are worded incorrectly or request unnecessary information, the form may become confusing for the form-filler and may negatively influence the completion of the document.



It is important that design decisions are implemented consistently. If a given typeface of a given weight (ie. 12 pt Helvetica bold) is used for a title on the first page of a form, all other titles of a similar hierarchical level should also be in the same typefont (ie. 12 pt Helvetica bold). Consistency in typographic and graphic hierarchies and cues, allows form-fillers to move through the form more easily. (Barnett 1984: 119, 139)

## Colour on forms

*“Colour is information. We stop at red lights and move on when they change to green ... We respond to colour: our colour preferences are keys to buried emotions.”*  
(Barnett 1989C: 2)

Colour is one consideration which can enhance or hamper legibility. Colour should be used in combination with other graphic and typographic features to improve a form's design, and should not be relied on as the only source of information coding on a form. Colour should be used when and where it serves a practical purpose for the form-filler or processor.

Colour psychology tests are generally conducted with mass colour and the suggestions made based on the results of these tests do not necessarily apply to forms. When selecting colours for forms, it is important to consider the legibility of the printed data on the paper, the legibility of the handwritten data on the paper, the contrast between the printed data and handwritten data on the paper, the aesthetic appearance of the ink colour with the paper, and the reproduction needs of the data. (Will it be photocopied or faxed?)



According to Barnett, “the key to good legibility is contrast and the best legibility comes from black ink on pastel yellow paper.” (Barnett 1989C: 27) Following are some other basic colour considerations related to the design of forms:

- “Bright yellow should be avoided because it can be emotionally disturbing to some people when read constantly. It can also cause nausea.” (Barnett 1989C: 29)
- “Pastel yellow paper (canary yellow) is not a problem.” (Barnett 1984: 28)
- “Commonly used paper colours such as pink, green and buff have been shown in scientific legibility tests to reduce legibility but this does not necessarily mean that they should not be used.” (Barnett 1984: 28)
- “It is known that small print in red is much more difficult to read than colours such as blue, green or brown. For this reason, it is not recommended as a text colour for forms.” (Barnett 1989C: 17)
- “Green is the most restful colour to the eye ... The lens of the eye focusses green light almost exactly on the retina.” (Barnett 1984: 31)
- Blue based colours appear darker than other colours because of the way the retina receives light signals. If a colour other than black is desired, a colour in the reflex blue range (a dark blue with some purple tint) allows for good colour contrast with a white background. (Barnett 1989C: 16)
- Most blue pens use an ink with a hue similar to reflex blue. (Barnett 1984: 28)
- Dark greys have been found “to be better for text than black, especially when used with a pastel coloured background on white paper. Grey is not as intense as black and makes for easier reading.” (Barnett 1989C: 30)
- “Colour can guide the users to fill in a form in the right places and assist them to bypass areas that don’t need to be filled in.” (Barnett 1989C: 26) The Communication Research Institute of Australia has had positive psychological reactions on public forms that had pastel coloured backgrounds with white boxes for the sections to be filled in by the public.





- It is important to consider if the users of the form have colour vision problems. “Very few people are technically colour blind. Most people with colour vision problems are simply colour deficient [confusing different hues] ... The most common problem is confusing red and orange with yellow and green.” (Barnett 1984: 27, also see Barnett 1989C: 16 -19 for a brief synopsis on how the eye perceives colour)

Paper colour, surface and weight will also affect the legibility of the form. “The general appearance of the front of the form may determine the attitude of the form-fillers’ to the remainder.” (Barnett 1989A: 13) Some colour combinations may be unpleasant to many people and may therefore influence their desire to complete the form. “Matt papers generally produce a loss in saturation or strength of the colour and this is always combined with some greying of the colour and usually a change in the actual hue.” (Preucil 1961a cited in Barnett 1989C: 10) Light weight paper can result in show through from the back of the form and therefore reduce legibility.

## Instructions on forms

Many people do not read instructions, even if short. Instructions tend to be skipped especially if the reader feels they are routine. (Barnett 1989A: 13) If the instructions are important, the form must be designed so that it constrains the form-filler to read them. For example, instructions for specific questions should be positioned where the form-filler needs the information, and not only at the beginning of the form.

“[O]rder [of] information is much more critical for carrying out instructions correctly than for remembering them accurately”  
(Wright 1994: 1.6)



Lengthy questions and instructions can also create problems. According to Robert Barnett from the Communication Research Institute of Australia, the reader may simply skim over the text “picking up the first few words, and making a rapid decision on its relevance.” (Barnett 1989A: 14) This skimming of lengthy texts may result in decisions and responses that are inaccurate. Having said this, short instructions are not necessarily easier than long ones. Longer instructions can provide more relevant information and can be easier to follow than short ones. (Waller 1984 cited in Barnett 1989A: 14)

## Types of questions

There are many ways in which questions can be asked and answered. For example, the response to “Where do you live?” could be interpreted as a street address, as a type of building, or the name of a city.

There are different methods of providing responses such as ticking boxes, writing answers or deleting what does not apply. The choice of the answer method depends on the means of completion, the use of the answer, the mode of answering and the form-filler. (Forms Information Centre 1985B)

Matrices involve additional memory processes than simply providing one’s age, for example, and should be considered carefully when used on a form. “It is obvious that answering questions involves memory processes. Even responding with your name and address necessitates retrieving this information from long term memory. What is less obvious is that the display of the questions themselves may involve additional memory processes.” (Wright 1981A: 166)



The example of different question styles shown below is from a membership application form for the Book-of-the-Month Club. The section of the form shown here is represented at actual size. There are examples of questions which are open-ended (Name, Address), yes/no, check which apply (mail-order purchases) and circle which apply (matrix of literature preferences) on this form.

**FIGURE 7**

Name \_\_\_\_\_

Address \_\_\_\_\_ Apt. \_\_\_\_\_

City \_\_\_\_\_ Prov. \_\_\_\_\_

Postal Code       All orders subject to approval.

**INDICATE YOUR 4 BOOKS BY NUMBER:**

—
—
—
—

**C-4-520-01**  
**5-A1**

**Present Member:**  
Choose any 2 books from this News, and we'll send them to you as soon as your friend is enrolled.

**INDICATE YOUR 2 BOOKS BY NUMBER:**

—
—

**3-70**

**NEW MEMBER SURVEY**  
(Please circle one number for each category.)

	1	2	3	4	5
<b>A. Mystery/Suspense Fiction</b> (P.D. James, Agatha Christie, Stephen King)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>B. Popular Fiction</b> (Maeve Binchy, James Michener, Margaret Atwood)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>C. History, Biography, Politics</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>D. Self Help</b> (How-To, Human Behavior, Language, Health)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>E. General Interest</b> (Science, Philosophy, Religion, Classics, Poetry, Reference)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>F. Family and Fun</b> (Cookbooks, Crafts, Art, Travel, Pets, Humor, Children's books)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>G. Business, Finance</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>H. Sports</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you have a telephone? ☐ YES ☐ NO

Have you ever bought anything by mail in the past?  
☐ YES ☐ NO

How have you paid for your mail-order purchases?  
(check all that apply)

☐ CASH ☐ CREDIT CARD ☐ CHECK ☐ MONEY ORDER

**#011**

According to Patricia Wright, questions that thematically relate should appear together. It must be apparent to the form-filler where the answers are to be written. The form-filler needs clear signposting to move from one question to the next. Questions can be numbered, subheadings can be used or the space can be physically rearranged for a more visible sequence. (Wright 1981A: 158)

Problems arise when questions have many parts. The simplest solution is to ask separate questions.

It is advisable to use positively rather than negatively worded questions. Research has shown that people respond faster if





they are able to respond to the items that do apply rather than deleting those that do not. (Barnett 1984, Orna 1983, Wright 1981A)

## Delimiters

The term delimiter is used to refer to “a mark used to limit the space in which a character can be entered on a form.” (Barnett 1984: 39) Delimiters have traditionally been used on forms in the computer industry. They can be useful when it is likely that information will be entered in the wrong space, when more detail may be provided than is necessary, or when data collected on forms is to be inputted.

Following are two examples of commonly used delimiters. Figure 8 illustrates an example of tramline delimiters and figure 9 is an example of box delimiters.

FIGURE 8

From 

--	--

--	--

--	--

 To 

--	--

--	--

--	--

Day      Month      Year                      Day      Month      Year

Forms often incorporate delimiters when dates are requested. Delimiters may also be used to assist the form-filler in completing a request, such as entering a code on a touch tone phone, as the example below from the University of Alberta telephone registration form.

FIGURE 9

Drop Code	Star Key	Catalogue Number	Pound Key							
<table border="1" style="display: inline-table;"><tr><td>D</td></tr></table>	D	<table border="1" style="display: inline-table;"><tr><td>*</td></tr></table>	*	<table border="1" style="display: inline-table;"><tr><td> </td><td> </td><td> </td><td> </td></tr></table>					<table border="1" style="display: inline-table;"><tr><td>#</td></tr></table>	#
D										
*										
#										

Delimiters force the form-filler to write just one letter in each space provided. This creates problems with legibility because the shape of the word is disrupted. The use of delimiters may also create problems when not enough space is provided, or if the form must be typed.



The following example is taken from the 1994/95 Alberta Student Loan application form which requests the name of the school where the student has studied and is studying, but provides inconsistent delimiters (15 and 18 spaces respectively) for this information. In order to provide the requested information in either case, the information must be abbreviated.

FIGURE 10

Name of School	Program/Faculty	From	Attended	To
UNIVERSITY OF ALBERTA	VISCOMM DES/ARTS	09	85	04
		Month	Year	Month
				Year
FOR THE 1994/95 SCHOOL YEAR I WILL ATTEND FULL-TIME				
Name of School	City/Town			
UNIVERSITY OF ALBERTA	EDMONTON			

Delimiters should be avoided unless absolutely necessary. If delimiters are required, research conducted by Barnett suggests that two dots, like a colon, be used to separate entry areas instead of solid lines or boxes. (Barnett 1984: 39)

Administration of forms

While the major concern of this thesis is related to facilitating the dialogue which occurs between the form-filler, the Advance Directive form and those who may be in a position to act on the instructions in the Advance Directive, concerns related to the administration of forms in general should also be considered. The information provided on business and government related forms is often used by more than one section of an organisation. Forms may have several copies which are colour coded for different departments.

The information provided on the form may be transcribed by an administrator, inputted by a data processor or scanned by an optical character reader (OCR). The sequence that information is requested in, or the manner in which the questions are asked, depends upon the end use of the information.



## Specific aspects of Advance Directive forms

Unlike most other forms, Advance Directives deal with emotional subject matter. Individuals must consider the possibility of their own potential serious illness or even death. The people who complete Advance Directives in Alberta, have chosen freely to fill out these forms. They are usually not required or forced to do so. An Advance Directive is not completed quickly nor immediately like an order form. Considerable thought and contemplation usually occurs before the form-filler completes the Advance Directive.

On most other forms, such as business and government forms, it is possible to test for errors. With Advance Directives, errors are difficult to analyse. What is important on Advance Directive forms is the form-fillers comprehension of the information and the decisions being made.

Because Advance Directives are not commonly in use, general information about what they are, how they differ from Last Wills, and what may be included on them must be provided to those wishing to complete an Advance Directive. In addition to this information, specific information should be given regarding the legal status of Advance Directives in Alberta.

Once this factual information has been provided, information of a more personal and emotional nature should be presented. Reasons why an individual may choose to complete an Advance Directive should be mentioned, as well as a general discussion of death and dying. Information regarding specific life-sustaining treatments and how changing one's mind affects the process should also be discussed. In addition, the form should include instructions about what to do with an Advance Directive once it has been completed, and how to let others know that it exists.

Advance Directives are important documents and the directions given in them should not be considered lightly.



Like many other forms, people may approach Advance Directives with preconceived ideas about their responses. Because the decisions being made on an Advance Directive may be of a life and death nature, it is imperative that the form-filler be provided with the information he or she requires to make those decisions. This information must be presented in a clear and understandable manner.

Clarity of language is crucial. The language should avoid legalese and medicalese. "Information may be very complex, and the doctor may feel that it is nearly impossible to present a balanced view of the problem without injecting a high dose of anxiety." (Burnell 1993: 102) Individuals completing Advance Directives should be encouraged to ask questions about information they do not understand.

The discussion of the subject matter must be presented in a sensitive, yet informative way. The information must be presented in such a manner that it is neither too detailed nor too general for the individual completing an Advance Directive.

"[I]f given assistance in interpreting information and knowledge, most people can understand technical information sufficiently to make intelligent treatment decisions. ... They need information, and doctors and nurses are the ones who control the flow of information." (Burnell 1993: 100-1)

The phrase Advance Directive is at present not commonly in use. In addition to designing Advance Directives which are helpful to individuals who wish to complete them, an information campaign must be developed to increase public awareness of Advance Directives. This information campaign must define Advance Directives as well as discuss the specifics of the proposed legislation.





## Design criteria for document development

Based on the analysis of existing forms and discussions with legal, medical and potential users, an Advance Directive form was developed which addressed a number of concerns. The concerns addressed include the importance of clear and understandable language, an accessible layout, sufficient information to make decisions, information from an Alberta perspective, the presence of both a proxy and instruction directive section, the inclusion of a section to indicate who has a copy of the Advance Directive, space to provide a personal statement, and enough space to provide information.

The Advance Directive form has been designed as part of a total information package. In addition to the form, the package contains an information booklet which briefly discusses the key issues to consider when completing an Advance Directive. The information design process included developing, writing, sequencing and formatting the content of the package. The package is intended to initiate dialogues between the form-filler, their family, healthcare proxy and healthcare providers, as well as their friends, lawyer and spiritual advisor.

Although some people believe that an Advance Directive condones euthanasia, this is not true. It is legal to refuse medical treatment, which may be directed on an Advance Directive, but euthanasia, as discussed previously in this paper, is illegal in Canada. Because of the various connotations the term “euthanasia” invokes, it was decided not to use this term nor to include information about euthanasia in the package.

The booklet begins by introducing Advance Directives, differentiating between an Advance Directive and a Last Will, and discussing why an individual might choose to complete an Advance Directive. Once Advance Directives have been introduced, the subject of thinking about death and dying is presented. Further information is provided regarding questions to ask doctors and healthcare providers, questions to ask lawyers, types of life-sustaining treatments, Alberta’s



proposed legislation and what to do with an Advance Directive once it is completed.

Initially the booklet was designed to have two columns: one wide column for the main body of text, and one narrow column to highlight keywords and definitions. As the content of the booklet was refined, it became apparent that the narrow column was not necessary. The text was written in such a manner that the language would be clear to a majority of the readers, and the need for singling out key terms in the margin became unnecessary. In this case, highlighting specific terms in the margin could hamper the communication process by disrupting the visual environment. The form, however, different from the booklet has marginal notes in a narrow column to distinguish between the instruction area and the text in the response area, which is formatted in a wider column.

The form was designed to fold down to an 8 1/2 x 11" format. This size was chosen because it is a standard size, and is easy to file and photocopy. The information booklet's format was designed to correspond with that of the form.

People often associate legal documents and forms with "small print." The text for the Advance Directive form designed for this package was set in a size which is easily readable by the majority of people (9 pt for the general instructions and 13 pt for the questions). The general instructions were set in a sans serif typeface (Stone Sans semibold) and the questions were set in a serif typeface (Adobe Garamond). These typefaces were selected to further differentiate between question and instruction areas on the form.

Consideration has been given to both the possibility of individuals typing or handwriting their responses. Sufficient space (24 pt line-spacing) has been provided to allow for both possibilities. The common linespacing on a typewriter is 12 pt, so the line-spacing on the form would allow for double-spacing if the form was typed.



## Content development

*“With effective communication as the goal, writers and designers are expected to take increasing responsibility for both the verbal and visual aspects of their work.*

*The need to relate more complex information to a greater variety of audiences demands that writers and designers expand their individual roles and collaborate in formerly unexpected ways.” (Carnegie Mellon University 1995: 1)*

In “Writing to Inform,” Liz Orna states that:

- “Those who design information need to be able to: Present information coherently in writing themselves.”
- “The publication of information is a series of transformations, starting from the original ideas and ending with the final printed version which reaches the user. At each stage, specialist skills are applied by different people.”
- “Readers bring to what the writer offers their own experience, and their own expectations of what they are going to get from reading.”
- “Do not expect the readers to dig for information; make a clear path for them to follow.”
- “Experiments show that instructions which are explicit and positive are the easiest to act on.”
- “When introducing unfamiliar ideas, make logical connections to help the reader move from familiar ideas to new ones.”
- “Readers found it easiest to manage ‘language that is active rather than passive.’” (Kirkman 1980 cited in Orna 1983)

The Document Design Center of the American Institutes for Research approaches document design by setting the context for the reader so that the reader knows what is contained in the document, why they might choose to read the document, and what the purpose of the document is. The Center



suggests not to tell people how to do something, but “tell them why and under what circumstances they might choose to do something rather than something else.” The Center also suggests the use of questions as headings. “Don’t be afraid to repeat sentences, paragraphs, or whole pages if it will help your readers get what they need efficiently.” (American Institutes for Research 1983: 1-3)

When completing an Advance Directive, the form-filler requires sufficient information to make decisions about the possibility of their own serious illness or death. The information must be presented in a clear and understandable as well as sensitive manner because of the nature of the information being discussed.

It is also important to consider cultural context when discussing death and dying. For example, within Chinese culture it is considered bad luck to think about future health problems.

“The fear of death is universal. We manage not to think about it very often. As we go through life, we tend to think that life is endless and that the ending is rather abstract – something that happens to other people, not to us.” (Burnell 1993: 28)





## Development of testing materials

The target user group for this type of document is broad, and could encompass all competent people living in Canada who have reached the age of discernment (generally considered to be 18 years of age). For the purposes of this study, the form was designed for persons 55+ who are in good health and have chosen to complete an Advance Directive. This group was selected because they are likely to be planning for their future in the event that they become unable to make their wishes known to those around them.

The form and information booklet incorporate established design principles. These principles address issues of legibility, readability, function and aesthetics. They include the consideration of typography, line length, format, layout and colour.

Typefaces were selected which were clearly distinguishable from one another and were legible. Because of the target age group, a large type size and handwriting space were incorporated in the design. (Forms Information Centre 1984C)

“Visual acuity declines with age, which means that many older users need a marked contrast between an image and the ground on which it appears. Middle-aged users often have problems because they have not yet come to terms with their difficulties in reading or do not have their correct spectacles [at] hand. Such readers are likely to find pale colours, such as pale blue, pink and yellow, even more difficult to perceive than younger readers do. Moreover, they will not be helped by tinted papers. Their problems are likely to be increased when type sizes are smaller than those normally used for texts of novels and when levels of illumination are low.” (Forms Information Centre 1983: 8)



Black was chosen as the text colour to provide a strong contrast with the paper and to allow for photocopying of the document. Due to the age group of the test subjects, a strong contrast between text and background was important to consider.

A natural white paper was selected to provide sufficient contrast with the black type. A 10% black screen was used to separate the instruction areas from the question and response areas of the form.

A 27 pica line length was chosen, making the main body of text approximately 55 characters per line. This line length provided consistent line endings and sufficient characters to read and comprehend the text.



## Testing

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### Testing procedure

The subjects of the study were members of the Society for the Retired and Semi-Retired in Edmonton who were approached to participate in a study about Advance Directives. They were each given a copy of the Advance Directive Package and asked to take it home to review the information. They were also asked to complete the form included in the package, but not to sign it nor to have it witnessed. When they were given the package, a date was set for a follow up interview regarding their responses to and thoughts about the Advance Directive Package.

Each subject was interviewed at the Society for the Retired and Semi-Retired. Interviews were set up to coincide with days that each subject volunteered or worked at the Society. The interviews were conducted in a location where the subject felt comfortable and where it was convenient for the subject to meet with the interviewer.

Prior to distributing the packages, a statement was prepared which was read to each subject. If the subject agreed to participate in the study, they were given a package to take home and review. During the introduction and distribution process, it became immediately apparent that the subjects were uncomfortable with taking home the Advance Directive Package without initially viewing the form.

The introduction process of the study was adapted in progress to accommodate the subjects' concerns. The subjects were given the package to scan briefly, and the last paragraph of the prepared statement was read to subjects before they were asked if they would be willing to participate in the study. If the subjects were willing to participate in the study, they were then given a consent form to review and sign which acknowledged their understanding of the study.



## Results

During the return interviews, most subjects talked about the death of a loved one which they had recently experienced. Many talked about experiences in their lives, such as their career or hardships they had faced.

All subjects were presented with colour mockups of the form near the end of the interview. Some subjects reacted positively to the use of colour, while others felt black and white worked just as well.

All subjects said they felt comfortable with the information presented in the package, but that some people may feel uncomfortable thinking about death and dying. Most subjects said that they could only speak for themselves.

### Subject one

Subject one was a 74 year old married woman with children. The interview was conducted in an office in the library of the Society where the subject was volunteering for the afternoon.

The subject had worked as a legal secretary prior to retiring, and her daughter had previously completed a masters degree in medical administration. The subject was aware of Living Wills because of working in a law office, but she said “the ones [she] saw were quite basic compared to now-a-days.”

When the package was distributed, she had two articles about Living Wills and a letter from the Society’s lawyers to the Minister of Health regarding concerns about the proposed legislation to give to the interviewer. At the second meeting, the subject gave the interviewer a magazine distributed to seniors in Alberta which contained an article about the proposed legislation.

She was the only participant who typed her responses on the form. She was also one of only two participants who noticed a typographic error on the proxy page of the form.





Subject one had a suggestion for improving the wording on page one of the booklet. She felt that the proxy section of the form may be a problem in some families and could cause conflicts.

The subject said that list set ups in the booklet were helpful, but more spacing between points could improve legibility. She had no concern with the use of capital letters for key terms.

When shown colour mockups of the form, the subject reacted positively to the use of an aqua green field to separate the form instructions from the area to be completed by the form-filler. She felt the use of the green was more attractive and inviting. She did not have a problem with the legibility of the black type on the green ground.

On the proxy directive page of the form, she typed in the name of the person she would like to make decisions for her if there was a disagreement between her proxies, but she did not tick the box associated with this response.

The subject believed that the Advance Directive Package broadened the information she already knew. She thought that the table of contents and the appendices were well set up. The subject felt that the questions to ask one's lawyer and doctor were particularly helpful, as well as the section on where to keep one's Advance Directive.

## **Subject two**

Subject two was a 77 year old single female with no children, and no immediate family. She had thought about completing an Advance Directive, but to date she had not done so. She was a great believer in euthanasia. The subject had to attend a funeral the day following the interview.



Subject two was interviewed in the reception area of the Society where she was volunteering. She expressed the most concern when she was introduced to the study. Although she had been told that it was not necessary to sign the test form, she was concerned about the implications of signing the form.

The subject also expressed concern about completing the proxy section of the form in case someone saw it. She was instructed that it was not necessary to provide real names, and she could simply use an arbitrary name such as Jane Smith. She was also told that the proxy section of the form was optional.

The subject was concerned that the package did not address when an individual is not terminally ill, seems to recognize those around them, but is unable to communicate either verbally or physically.

She only completed the first two situations of the instruction directive page of the form, and did not complete the rest of the page because of her concern mentioned above. The subject stated in the interview that she would have provided the same instructions for the last two situations as her response to the second situation on the instruction directive page.

The subject did not believe that colour would make a difference to people completing the form, but she did think example pages could help.

### **Subjects three and four**

Subjects three and four were interviewed together in between answering telephone calls at the switchboard. Both subjects forgot their packages at home. Subjects three and four did not necessarily hear each others responses, because while one subject was answering questions, the other subject was usually answering the telephone.



Both subjects three and four wanted to know why they were always asked for their age on forms. Even on the form for the exercise class they were taking, they had been asked how old they were.

When the interviewer returned the following week to retrieve the packages from subjects three and four, both subjects said that the information provided in the package had helped them to initiate discussions between themselves and their families. They had also discussed their ideas about Advance Directives with friends.

### **Subject three**

Subject three was interviewed at the same time as subject four, as mentioned previously. Both subjects had forgotten their packages at home, but were able to answer the interviewer's questions with the assistance of a sample package.

Subject three was a married female over 65 years of age who had children. She said she had completed the test form, but she already had definite ideas about life-sustaining treatments even though she had not personally completed an Advance Directive. She said she was aware of "lots on the news that has happened over the last couple of years."

The subject stated that she should really complete an Advance Directive to make others aware of her wishes. She said she had discussed her wishes with her chiropractor, but not with her general practitioner.

The subject believed that all the information seemed helpful, but that it did not really help her to fill out the form because she already had her own ideas regarding life-sustaining treatments. The subject felt that each situation in the instruction directive part of the form could have the same response.



She stated that page five of the booklet, things to ask yourself about death and dying, was quite important as she was reading through the booklet. The subject also felt that the information presented in list format was helpful.

She felt it was easy to read and “my eyesight isn’t anywhere near perfect.” Subject three did not believe that colour would be of any assistance when completing the form, and she stated that the black text on the green field was more difficult to read. “Pure white is better for anyone with a vision problem.”

She believed that example pages of a completed form could be helpful, but that people might tend to write the same thing. The subject also believed that having a copy of the proposed legislation in the package might be helpful.

### **Subject four**

Subject four was a 65+ widow with children. She was interviewed at the same time as subject three. Like subject three, she had forgotten her package at home. Unlike her counterpart, she said she had not had time to complete the form, but she had read the booklet and reviewed the form. Upon returning one week later as scheduled with the subject to pick up the package, the subject had not completed the form. She did not believe that any of the information was new to her, but it had made her think in more detail about Advance Directives.

The subject stated that “sometimes forms are really confusing, they have so much information in them that once you get through it all, you are confused.” She was not confused with this particular form.

The subject stated that “most people won’t bother with the proxy section.” She believed that the majority of people would complete an instruction directive only and would want





their doctor to make decisions for them. The subject felt the use of colour was distracting when she was presented with the colour mockups, and she stated that she liked white better.

The subject liked the use of lists in the booklet. She thought that example form pages in the booklet could be helpful, but that people might copy the responses. The subject also thought that having the proposed legislation in the booklet could be helpful, and she stated that “if people go this far, [considering completing an Advance Directive] they want to see what the legislation is all about.”

### **Subject five**

Subject five was a 69 year old widow with children. She did not complete the form because she had unexpected company, but she had read the booklet and thought about the form.

The subject has a handwritten Living Will attached to her Last Will. She also has two friends who have just recently had Living Wills made with the assistance of a lawyer. The subject said no one helped her complete her Living Will, but she had discussed it with her family and her lawyer. Her Living Will states that if she is terminally ill, she wants to be allowed to die naturally, and if she has brain damage, she does not want life support.

On the Advance Directive form in the package, she stated it was difficult to decide on personal beliefs because no one knows how they will die. On the instruction directive part of the form, she said the separation of the terminally ill and brain damage possibilities was helpful. The subject preferred the addition of colour on the form, and said that colour made the form stand out more so that one took more notice of it. She felt the teal green colour mockup was more inviting and attractive, and it was “attention getting.”



In the booklet, she thought the information presented about proxies was helpful, as well as the information on page five about death and dying. She said this information really makes a person stop and think. The subject stated page eleven, which presents the life-sustaining treatments, was also helpful.

She felt the addition of sample pages could be helpful and “may give you ideas of your own that you hadn’t thought about. Some people don’t know how to put their feelings into words, so a sample would help.” The subject also thought that the inclusion of the proposed legislation in the package could be helpful if it was written in plain English.

### **Subject six**

Subject six was a 69 year old single male with no children. The subject has an Advance Directive which a lawyer helped him to complete. He has only discussed his Advance Directive with his lawyer. He has planned to discuss it with his doctor, however, he has not as yet because he has forgotten to take the document with him when he has visited his doctor.

When the subject was given the package, he was using a magnifying glass to look up a number in the telephone book. He had no trouble reading the booklet or form he said.

The subject had not had time to complete the test form yet, but he stated he would complete it. He had reviewed the package, and believed that everything had been covered. When the interviewer returned one week later as scheduled with the subject, he had still not completed the form, but said he would do so by the following week.

When the interviewer returned the next week, subject six had completed the form. He had not filled in the proxy directive page of the form, because he wanted to discuss the matter



with the person who he would like to be his proxy. Like subjects three and four, subject six felt that the same response could be given for each of the situations presented on the instruction directive page of the form.

The subject did not believe that colour would make a difference when completing the form, and felt that “black and white does the job just as well.” He did, however, think that example pages of the form would be helpful, but doubted that having the proposed legislation in the package would be of assistance.

### **Subject seven**

Subject seven was a 62 year old married man with step-children. He was in the process of having an Advance Directive made, and had spent three evenings with a lawyer discussing specific situations. The subject stated that his Advance Directive was “my interpretation, but I want a lawyer who understands and can validate my interpretation.” He had discussed his Advance Directive with his wife and his lawyer.

Even though he had previous experience with the information presented in the package, he went back and looked at the booklet a couple of times when he completed the test form.

He did not believe that people in his age group would feel uncomfortable completing the form, but that groups determined by other factors may feel uncomfortable (ie. because of religious beliefs).

He stated that “colour diverts attention, detracts from the credibility of the document. Stay as clinical as possible. Keep as serious as possible.”

Subject seven stated that example form pages might be helpful, but they could be very detrimental as well.



“[The example pages] may take some people off the hook for making a decision. [These types of decisions are] something you should think deeply and clearly about yourself.”

Because interpretations are different, subject seven would only have the proposed legislation in the Advance Directive Package if it was in “layman’s language.”

### **Subject eight**

Subject eight was a 75 year old married male with children. He was one of two subjects who noticed a typographic error on the form.

The subject was a believer in euthanasia in certain circumstances. He expressed his belief that it is important to consider those left behind. If he became incompetent, but was in no pain and it was better for his family that he be kept alive, then that would be fine with him.

The subject stated that “there are older people that look at any document, they want to know what it is all about.” He said that the “What is an Advance Directive” section of the booklet was very important, especially the text about competency and the difference between an Advance Directive and a Last Will. He also said that the Healthcare Proxy section, the questions to ask oneself on page five and “How to prepare an Advance Directive” on page nine were helpful. The subject stated that “there is not much you could leave out, particularly if you are [addressing people who are] not familiar with the subject matter.”

The subject felt the booklet was chronologically well laid out, and that the “Thinking about death and dying” section could be moved to the beginning of the booklet, but it “might scare people off.”





The subject thought that both the addition of colour and example form pages could be helpful, but that adding the proposed legislation to the package could be confusing.

### **Subject nine**

Subject nine was a 68 year old separated male with children.

The subject stated that those who had recently lost someone might find it difficult to talk about death and could find the information distressing. He personally did not feel uncomfortable about completing the form, but it was “just difficult to answer the personal beliefs section, very philosophical.”

The subject felt that pages four and five of the booklet were helpful, and that these pages were the most sensitive and personal part of the package. He liked the brevity of the package, and thought the questions to ask one’s doctor were very helpful. The subject expressed his preference for information presented in list format instead of in paragraphs.

He did not believe that the addition of colour to the form or the inclusion of the proposed legislation in the booklet would be of assistance. The subject thought that the inclusion of example form pages in the booklet could be helpful.

The subject suggested the addition of five or six more lines to the personal beliefs section of the form. He stated that he did not want to appoint a proxy, but he did not see a place to state this on the form, nor was there a place to state who he did not want to act as his proxy. He was also concerned that if he was declared incompetent, how could he be declared competent?

The subject stated “I think it [the package] would save a person money, because they could make up their mind pretty well before seeing a lawyer.”



## **Subject ten**

Subject ten was an 83 year old married female with children. During the introduction of the study to the subject, the interviewer spent 45 minutes mainly listening to personal accounts of death and dying which the subject had experienced, as well as her family history. The subject called the interviewer two days before the scheduled interview, to reschedule because she had to attend the funeral of her sister-in-law.

The subject's hands were unsteady, yet she had sufficient space to complete the form. Like subject one, subject ten indicated who she would want to make decisions for her if there was a disagreement between her proxies on the proxy directive page of the form, but she did not tick the box associated with this option.

Subject ten felt the information provided in the package was very helpful. She believed the addition of colour, the inclusion of sample completed form pages, and the inclusion of the proposed legislation would all assist those wishing to complete an Advance Directive.



## Recommendations

*“Good information design means we must understand specific information users and specific contexts of use. This is no different from good conversation which requires us to understand our partners in the context in which we are talking. Developing good conversation, though, is sometimes easier than developing good information design. In conversations, the participants have the opportunity to question and clarify content and modify understanding as the conversation proceeds. With information design, there is not the same opportunity for such fine tuning at the moment of production. Instead, it is necessary to seek out the users and observe them using the information and then make changes before the final version is developed. And then the process of review and revision must continue throughout the information’s life.” (Penman in Sless & Penman 1994: vi)*

The subjects who participated in the study all agreed that the Advance Directive Package would be of assistance to someone who wished to complete an Advance Directive. They indicated that the information was presented in a clear and understandable manner, the type size was easily readable, and that sufficient information was provided.

The subjects were able to find the information they needed to complete the form. Although some subjects stated that the information was not new to them, they said it made them think about what they would or would not want in certain situations. The subjects did not find the information distressing.



Following are issues which were raised during testing and recommendations to address the concerns:

- The subjects liked the use of lists to provide information in a succinct manner. They especially found the questions to ask their doctor and lawyer helpful, as well as the list of life-sustaining treatments. Subject one suggested that this list would be easier to read if there was more space between the points.  
**It is suggested that all lists in the package be reviewed, and that more leading be added as required.**
- Several of the subjects who completed the form, stated that they would want the same life-sustaining treatments in all situations presented on the form.  
**As a result of comments made during the interviews, it is suggested that a statement be included in the booklet which indicates why the form-filler may want or not want specific treatments in different situations.**
- On the proxy directive page of the form, both subjects one and ten included the name of the person they would like to make decisions for them if there was a disagreement between their proxies. Neither subject ticked the box associated with this option.  
**Either the instructions should be moved into the question section of the form, or the tick boxes should be given more prominence.**
- Also on the proxy page of the form, some subjects asked what they should do if they did not want anyone or a specific person to act as their proxy.  
**The proxy part of the form should be redesigned to include a section where the form-filler can indicate that they want their doctor to make decisions for them if they are incompetent, and where the form-filler can identify those individuals they do not wish to act as their proxy.**





- Some subjects reacted positively to the use of colour on a form they were shown during their return interview, while others felt black and white worked just as well. All subjects referred to the paper colour as “white” although the paper was actually natural white (not bleached) and not bright white.

**Further study should be conducted in relation to the use of colour on Advance Directives. Does the addition of colour assist the form-filler to complete the form? Does it add an aesthetic appeal which improves the form-filler’s perception of the form, or does the addition of colour trivialize the form in the eyes of the form-filler?**

- Most subjects felt that example pages of a completed form in the information booklet would be helpful. Some subjects were concerned that people would simply copy information presented on the example pages instead of thinking about their own beliefs.

**It is suggested that example pages of completed forms be included in an appendix in the information booklet, and that further research be conducted regarding their use.**

- All subjects who completed the form, filled in the personal beliefs section. They understood what to include, but they felt that this section took some time to consider. One subject said he could have used five or six more lines for this section.

**It is suggested that more space be provided and that instructions be included on the form which state that the form-filler may include additional pages if necessary.**

- Subjects were uncertain whether the inclusion of the proposed legislation in the package would be helpful. The majority felt that the legislation would create more confusion for anyone not familiar with legal language. **It is suggested that the proposed legislation not be included, but that the references to the legislation remain in the package.**



In addition to the recommendations determined through testing, it is suggested that educational campaigns be developed for all the potential users of Advance Directives. Campaigns for healthcare providers including doctors, nurses, social workers and staff in longterm care facilities, for legal professionals, and for those wishing to complete Advance Directives should be implemented.

A card should be developed and included in the package for the individual completing the Advance Directive to carry with them at all times. This card would indicate that the individual has an Advance Directive, and provide information related to its location.

It may also be advisable to consider testing an Advance Directive Package with a variety of forms in it, but only one information booklet. The individual wishing to complete the Advance Directive would thereby have the opportunity to choose the form that is most consistent with their needs.



## Conclusion

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*“Good design is often invisible, in the sense that readers have no appreciation of the problems that were solved and no realisation that the information could have been presented in other ways.” (Wright 1994: 1.4)*

The value of thinking about design issues throughout the development process of information documents, is in reducing the number of revisions that are required. The main cause of ineffective forms according to Patricia Wright “most probably lies in a failure to appreciate the range of skills required for achieving a satisfactory design in which so many interests have to be reconciled.” (Wright 1981A: 6)

Although this project began by attempting to develop an Advance Directive form, the research conducted resulted in a more comprehensive approach to presenting information about Advance Directives. Because of the complexity and the nature of the information required to provide informed consent, it is suggested that an information booklet accompany the Advance Directive form. This booklet is intended to provide information about the key issues to consider when completing an Advance Directive for the benefit of those who want this information.

Advance Directives are examples of critical-use documents. They must be usable and accessible to all potential users of the form, because when they come into effect, the administrators of the form may have to make decisions of a life and death nature.

Currently, Advance Directives are usually written documents, but in the future it may be possible to carry all of one's healthcare history, including one's Advance Directive on



a card which any medical facility would be able to access by inserting this card into an electronic reader. Advance Directives may also be recorded on video or audio cassettes in the future. Whatever format an Advance Directive may take, it is important that sufficient information has been provided to make informed decisions.

The most important part of this critical-use document, whether it is written or otherwise, is not the form itself, but the dialogue that it initiates between healthcare providers and the person completing the Advance Directive, as well as with his or her family, friends, healthcare proxy, lawyer and spiritual advisor. This Advance Directive Package is intended to help initiate and formalise these discussions.





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## Appendices

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### Appendix A: The prepared statement read to each subject



Thank you for participating in this study.

My name is Corrie Heringa, and I am a graduate student at the University of Alberta specializing in Visual Communication Design.

You are helping to test a proposed Advance Directive information booklet and form. It is important for you to realize that it is the performance of the Advance Directive information booklet and form which is being tested, and not your performance.

You are not required to complete this study, and you may opt out at any time.

The information you provide will be kept confidential, and no names will appear in any report related to this project.

The purpose of this study is to determine if the proposed designs provide the information needed to make an Advance Directive in a clear and understandable manner.

I would like you to take this information package home with you. Please review the information booklet and complete the Advance Directive form. You may take as much or as little time as you wish.

Please realize that you may feel uncomfortable with some of the information provided, because you will need to consider the possibility of being seriously ill or dying.

The Advance Directive form which you complete will only be used for study purposes and will not be used as an actual Advance Directive.

Your participation in this project will assist in pinpointing any problems with the content and format of the package. With your assistance I hope to develop an information package about living wills that will be relevant and understandable to the citizens of Alberta.

*Do you have any questions?*

If you feel that you understand the information I have provided, and you feel comfortable participating in this study, I would like to ask you to complete this consent form.

I would now like to establish a time to meet with you once you have completed the Advance Directive. At this meeting I will ask you some demographic questions as well as specific questions about the Advance Directive Package.

If you need to contact prior to our next meeting, you may call me at 436-4968. If I am not at home, please leave a message on my answering machine.



## **Appendix B: The consent form given to each subject**





Name

---

Telephone

---

I understand that my participation in this study on Advance Directives is voluntary and that I may opt out at anytime. The reasons for the study and tasks to be completed have been explained to me. I understand that the information I provide will be kept confidential, and that no names will appear in any report related to this project.

I agree to return after I have reviewed the information package and completed the Advance Directive form to answer some questions related to their content and format.

If I decide to opt out of the study, or I need to reschedule my meeting, I will contact the researcher, Corrie Heringa at 436-4968.

The time for meeting about content and format of the Advance Directive package

---

Signature of participant

---

Date

---



## **Appendix C: The Advance Directive Package**

The package was slightly modified after testing. The actual test package was a folder with the Advance Directive booklet and form in it.



# **The Advance Directive Package**

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## **An Alberta perspective**



## **Appendix D: The interview questions**

The questions asked during the interview with each subject after he or she had reviewed the Advance Directive Package.





Thank you for participating in this study. Today's interview will take approximately half an hour to complete. During this interview I will start by asking you a few demographic questions, and then I will ask you specific questions about the Advance Directive Package you were given on Thursday February 2nd to review.

You are not required to complete this study, and you may opt out at any time.

The information you provide will be kept confidential, and no names will appear in any report related to this project.

**Subject**

**Male/Female?**

**How old are you?**

**What is your marital status?**

**Do you have any children?**



1 Had you heard of Advance Directives before this study?

A Had you heard of Living Wills?

2 Do you personally have an Advance Directive?

A Did someone help you to complete it?

I If so, who?

B Have you discussed your Advance Directive with your family?

C friends?

D doctor?

E lawyer?

F spiritual advisor?

G anyone else?

3 Do you know someone who has an Advance Directive?



4 Did you read all of the information in the booklet provided?

5 Was it easy to read?

6 Was the type size legible?

7 Did you feel there was enough information given?

8 Did the information help you to complete the form?



9 Was the information presented clearly?

10 Were there any sections which were unclear?

11 Were there any sections which you found helpful?

12 Was it easy to find the information you needed in the booklet?





- 13 Do you feel that people in your age group would feel uncomfortable completing the Advance Directive form?
- 14 Do you feel that people in your age group would find any of the information distressing or inappropriate?
- 15 Do you feel that people in your age group would find any part of the form or booklet distracting?



16 Did you find the information on pages 4 and 5 helpful?

A If not, what would you change?

17 Do you think both page 4 and 5 are necessary?

18 Were pages which provided information in list form such as page 11, helpful?

19 Were any parts of the Advance Directive form unclear?



- 20 Do you think the addition of colour, such as this example (show mockup) would be of assistance when filling out the form?
- 21 Do you think that example pages of completed forms inside the information booklet would be helpful?
- 22 Do you think that it would be helpful to have a copy of the proposed legislation in this package?



23 Do you think this information package would be helpful for someone who wished to complete an Advance Directive?

24 Do you have any additional comments?

25 Would you be willing to participate further in this study when changes have been made to the Advance Directive Package?

A If so, may I contact you in the future at the number you provided me with earlier to set up another appointment?

Thank you for participating in this study. Your participation with this project will assist in pinpointing any problems with the content and format of the package. With your assistance I hope to develop an information package about living wills that will be relevant and understandable to the citizens of Alberta.





## **Appendix E: The slides of the exhibition**

Advance Directives: Accessibility and usability. The role of information design in the development of a critical use document.

The exhibition was displayed in the City Room of Edmonton City Hall from April 1 to 18, 1995.

- 1 Panel 1 (Information design)
- 2 Panel 2 (Form design)
- 3 Panel 3 (Advance Directives)
- 4 Panel 4 (Advance Directives)
- 5 Panel 5 (The Advance Directive Package)
- 6 Panel 6 (The Advance Directive Package)



# Advance Directive

When you have completed your Advance Directive, please consult with a healthcare professional to ensure that your instructions will be clearly understood.

## To my family, doctors, and all those concerned with my care

If a time comes when I am no longer able to make decisions for my own future, please use this Advance Directive as an expression of my wishes regarding healthcare decisions.

I make this Advance Directive being of sound mind, and I ask my healthcare providers to follow my instructions if it is within their power to do so medically and legally. I understand that I have the right to make healthcare decisions for myself as long as I am competent, and that I may revoke this Advance Directive at anytime.

Please print your name and address on the lines provided.

Name

Address

Please state your personal beliefs about living and dying in the space provided to the right.

You may wish to state your spiritual beliefs in this space. You may also wish to state how you would like to die if you had a choice. It may be important to you, for example, to die surrounded by your loved ones, or to die without pain.

## Statement of personal beliefs

## Instruction Directive

In this section please state your instructions regarding medical treatment in the event that you become unable to communicate them directly. You may wish to consult your healthcare provider to answer some of these questions

Please indicate the kinds of life-sustaining treatments you do or do not want for each situation.

Examples of life-sustaining treatments:

- Artificial nutrition and hydration (substitutes for eating and drinking)
- Blood or blood products
- Artificial respiration
- Cardiopulmonary resuscitation (CPR)

See page 11 of the booklet included with this Advance Directive package for more information regarding life-sustaining treatments.

If I am in my current state of health,

- ☐ I instruct that I be given medicine and other care to make me comfortable and take care of pain and suffering.
- ☐ I instruct that no life-sustaining treatments be used.
- ☐ other (Please specify)
- 
- 

If I have brain damage which my doctors believe to be irreversible, and which makes me unable to recognise people or to speak understandably,

- ☐ I instruct that I be given medicine and other care to make me comfortable and take care of pain and suffering.
- ☐ I instruct that no life-sustaining treatments be used.
- ☐ other (Please specify)
- 
- 

If I am unconscious and my doctors believe I have no known hope of regaining consciousness,

- ☐ I instruct that I be given medicine and other care to make me comfortable and take care of pain and suffering.
- ☐ I instruct that no life-sustaining treatments be used.
- ☐ other (Please specify)
- 
- 

If I am terminally ill, and I have brain damage which my doctors believe to be irreversible and which makes me unable to recognise people or to speak understandably,

- ☐ I instruct that I be given medicine and other care to make me comfortable and take care of pain and suffering.
- ☐ I instruct that no life-sustaining treatments be used.
- ☐ other (Please specify)
- 
-

## Proxy Directive

Your instructions may not cover all possible situations if you become incapable of making decisions for yourself.

It may be necessary for someone to accept or refuse medical treatments for you after consulting with your healthcare provider.

If you wish, you may name a proxy or proxies to make healthcare decisions for you if you are unable to do so.

In the space provided to the right, please indicate if you would like to appoint a healthcare proxy or proxies, and who you instruct may be or may not be your healthcare proxy. *(Please check the appropriate box or boxes)*

If there is a disagreement between your instructions in this Advance Directive and your proxy's or proxies' decisions, please indicate which decision should be observed. *(Please check one of the options listed to the right)*

If you have named more than one healthcare proxy and there is a disagreement between the decisions of your proxies, please indicate whose decision should be observed. *(Please check one of the options listed to the right)*

If there comes a time when I am unable to make healthcare decisions for myself,

- ☐ I would not like to appoint anyone to act as my proxy.
- ☐ I appoint the person or persons named below as my proxy or proxies. He, she or they should be consulted regarding my healthcare.

Name

Address

Daytime ☎

Evening ☎

Name

Address

Daytime ☎

Evening ☎

- ☐ I instruct that the person or persons named below **not** be appointed as my healthcare proxy

---

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If there is a disagreement between my instructions in this Advance Directive, and my proxy or proxies' decisions, I direct that

- ☐ my proxy or proxies have authority over my instructions.
- ☐ my instructions have authority over my proxy or proxies.

If there is a disagreement between my proxies, I direct that

- ☐ the decision of the majority of my proxies be used to determine any healthcare decision.
- ☐ the individual named below make any healthcare decision.

---

- ☐ other (Please specify)

---

---

in the presence of two people acting as your witnesses, please sign and date your Advance Directive in the space provided to the right.

Once you have signed and dated your Advance Directive, please ask your witnesses to sign and date it. In addition to their signatures, your witnesses should print their names and addresses, so that they may be contacted if necessary.

Please indicate in this section the names and telephone numbers of those people to whom you have given a copy of this Advance Directive.

This Advance Directive Package has been prepared according to the legislation in Alberta as of March 1995.

## Signatures

Your signature

Date

Witness signature

Name (Please print)

Address

Date

Witness signature

Name (Please print)

Address

Date

## Location of my Advance Directive

Name

Address

Daytime ☎

Evening ☎

Name

Address

Daytime ☎

Evening ☎

Name

Address

Daytime ☎

Evening ☎

# **The Advance Directive Package**

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**An Alberta perspective**

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## **What is an Advance Directive?**

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An ADVANCE DIRECTIVE is a written document where you indicate what healthcare treatments and procedures, including life-sustaining treatments, you want and do not want to have if you are seriously ill. An Advance Directive helps others make decisions for you on healthcare decisions you direct if you are not able to do so yourself.

Advance Directives are also called LIVING WILLS, ADVANCE MEDICAL DIRECTIVES, HEALTHCARE DIRECTIVES and POWERS OF ATTORNEY FOR PERSONAL CARE.

### **What does it mean to be competent?**

You may make an Advance Directive if you are COMPETENT. This means that you must be able to understand treatment choices and to understand their possible outcome. It is assumed that anyone who is at least 18 years of age is competent unless two doctors have determined that the individual is incompetent.

An Advance Directive only takes effect when you are considered INCOMPETENT. This means you can no longer understand treatment choices and their possible outcome.

### **What is the difference between an Advance Directive and a Last Will?**

The document is called an Advance Directive because it takes effect while you are alive. Your LAST WILL is a document where you provide your directions about what should happen with your estate and property when you die. In an Advance Directive you express your instructions concerning healthcare, to take effect when you are incompetent. An Advance Directive cannot be used to say who shall inherit your property or look after your children when you die. You should express these directions in a Last Will.

## **What are instruction directives and proxy directives?**

Advance Directives usually have two parts: an INSTRUCTION DIRECTIVE and a PROXY DIRECTIVE. An Advance Directive may also include an ORGAN DONATION part. DIRECTIVE is the term used in an Advance Directive for the instructions or directions you prepare about healthcare decisions.

The INSTRUCTION DIRECTIVE part of an Advance Directive is where you indicate what healthcare treatments and procedures, including life-sustaining treatments, you would or would not want in different situations.

The PROXY DIRECTIVE part of an Advance Directive is where you indicate who you want to make treatment decisions for you if you are no longer able to do so. The person you choose to make decisions for you is called your HEALTHCARE PROXY. The proxy is responsible for carrying out your instructions, so it is important that you discuss your wishes with him or her. The proxy should be someone you know and trust, like a spouse, partner, family member, or close friend.

You may name more than one person to be your proxy. If you name more than one person to be your proxy, you should indicate what should happen if your proxies disagree about medical decisions for you. For example, you may wish that the decision of the majority of your proxies be accepted, or that your spouse's decision take precedence.

An Advance Directive may also include an ORGAN DONATION part. If your Advance Directive comes into effect and life-sustaining treatments are stopped, you may wish to consider donating some of your organs to help others. If you feel that this is important, you should prepare an instruction directive about organ donation.

### **Do you have to complete all the parts of an Advance Directive?**

You do not have to complete both the instruction directive part and the proxy directive part of an Advance Directive, although they are complementary to each other. You may wish only to complete an instruction directive if you do not have anyone to appoint as your healthcare proxy. You may wish only to complete a proxy directive if you find it difficult to make specific healthcare decisions about life-sustaining treatments and you have someone who is willing to make these decisions for you.

### **Why are Advance Directives important?**

Advance Directives are important because these documents let your family, friends, healthcare proxy, healthcare providers, lawyer, and spiritual advisor know what is important to you when making decisions about medical procedures. When you are unable to make your wishes known and your Advance Directive comes into effect, these people can look at your Advance Directive and make decisions based on your directives.

Modern technology can keep patients alive even if they have permanent brain damage. Some people may wish to be kept alive with the aid of machines, hoping that someday they may be able to regain consciousness or that a treatment will be discovered for their illness. Others may prefer a natural death to what they would consider an artificial existence.

An Advance Directive expresses your decision of when to discontinue life-sustaining treatments if there is little or no hope of recovery.

An Advance Directive can also provide legal protection for your family and your healthcare providers. With an Advance Directive they can act confidently, in accordance with your

## Thinking about death and dying

---

Most of us tend to think about death as something abstract that is far away and inconceivable, something that happens to others, but not to us. If you have considered the possibility of your own death, you may have thought about the type of death you would or would not want.

The kind of death that you would want if you had a choice is sometimes referred to as an appropriate death. For some people the best possible death would be to die surrounded by their friends and family. Other people would prefer to die in their sleep or to die without pain.

You may find it uncomfortable to make an Advance Directive because you will have to think about your own serious illness or even death. You are making decisions now in the event that someday in the future you will not be able to express your wishes about life-sustaining treatments.

Decisions about medical procedures you want and do not want to have performed when terminally ill are different for everyone. Appropriate decisions can only be made when enough information is provided. This is why it is important to discuss your wishes not only with your family, friends, healthcare proxy and spiritual advisor, but also with your health care providers and lawyer.

**What should you ask yourself about death and dying when you are well?**

- Is withdrawing life-sustaining treatment against your personal or religious beliefs?
- Is life worth living if you have no brain function?
- Is life worth living even if this means you continue to live aided by machines?
- If you were terminally ill, would you wish to have every means available used to keep you alive?
- If you were terminally ill, would you like to die naturally?
- Do you think it is possible to have a good death as opposed to a bad death?
- Have you discussed your feelings about dying with your family?
- Have you considered who you would like to make healthcare decisions for you if you were unable to do so?
- Is it important for you to know how your doctor feels about life-sustaining treatment?
- Is it important to you that your doctor understands your feelings and wishes about your death?
- Would you be willing to express your wishes about life-sustaining treatments in writing?

If after answering these questions you find that making decisions about life-sustaining treatment is important to you, you should consider preparing an Advance Directive.

## **Who should complete an Advance Directive?**

---

You should consider making an Advance Directive if you want to maintain control over medical procedures being done to you. To make an Advance Directive you must think about the possibility of your own serious illness or death. Some people may find this distressing. You must decide for yourself whether completing an Advance Directive is right for you.

### **Who may complete an Advance Directive?**

It is assumed anyone who is at least 18 years of age and mentally COMPETENT can prepare an Advance Directive. Being competent means that you are able to understand treatment choices and their possible outcome. All adults are considered competent unless two doctors have concluded that an individual is incompetent.

If you are under 18 years of age, you should consult with your lawyer about making an Advance Directive in Alberta.



## Advance Directives in Alberta

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Many people believe that a healthcare provider must consult with family members about healthcare decisions for their loved ones. Although many doctors do talk to family members about treatments for their loved ones, they are not required to do so by law.

There is currently no legislation in Alberta specific to Advance Directives. If you have an Advance Directive, however, your healthcare providers would be in a better position to understand your healthcare wishes.

There is proposed legislation related to Advance Directives in Alberta. The proposed legislation is BILL 58: ADVANCE DIRECTIVES ACT. This legislation would make Advance Directives legally binding if it is within the power of the healthcare provider to fulfill the instructions given by the patient. The proposed legislation also includes an ordered list of people to contact if your proxy is not available. The legislation is expected to come into force in 1995.

If you are completing an Advance Directive, you may wish to consult with your healthcare provider or your lawyer to discuss the details of the proposed legislation.

## **How is your healthcare proxy determined in Alberta?**

In Alberta under the proposed Bill 58, when healthcare decisions need to be made for you, the first person available from the following list would make those decisions for you in consultation with your doctor.

- The person you have appointed as your healthcare proxy
- A guardian appointed under the Dependent Adults Act, if a guardian has been appointed for you
- Your nearest relative:
  - spouse
  - child
  - parent or guardian
  - sibling
  - grandparent
  - grandchild
  - uncle or aunt
  - nephew or niece
- The Public Guardian under the Dependent Adults Act

If your healthcare proxy is not available, the next available person from this list becomes your healthcare proxy. If you have indicated in your Advance Directive that you wish for a specific person not to act as your proxy, that person may not act as your proxy.

## **How do you prepare an Advance Directive?**

---

You can write an Advance Directive yourself at anytime as long as you are able to understand and appreciate treatment choices. Be sure to indicate your wishes about life-sustaining treatment should you become seriously ill.

When you are writing your Advance Directive, it may be helpful to discuss your concerns with your healthcare providers and your lawyer.

Consider discussing your Advance Directive with your healthcare providers before you sign your Advance Directive. You should ask what types of healthcare decisions could be made for you if you are unable to and you do not have an Advance Directive. Make sure you have all your questions answered so that when you complete your Advance Directive you can be certain that you are making informed decisions.

Be specific when stating your preferences about life-sustaining treatments. It is important to consider all of your choices carefully.

You do not have to use a specific form when you prepare an Advance Directive. You may use the form included in this package to prepare your Advance Directive.

**Who should witness your Advance Directive?**

After you write your Advance Directive, two people should witness your signature. Your healthcare proxy cannot be a witness for you.

Although you should discuss your Advance Directive with those close to you, you should not ask anyone who may benefit from your death to act as a witness for your Advance Directive. This would include anyone who would gain financially from your death, such as a beneficiary named in your Last Will.

You should consider having a NOTARY PUBLIC witness your Advance Directive. A NOTARY PUBLIC is a public officer who can certify documents to make them authentic. You may contact your lawyer about notary public services, or consult your telephone directory.

## **What are life-sustaining treatments?**

Some life-sustaining treatments which you may need when you are seriously ill are listed below. You should consider these carefully when completing your own Advance Directive. You may also wish to discuss them in more detail with your healthcare provider.

- **ANTIBIOTICS:** Treating infections with drugs
- **CHEMOTHERAPY:** Treating cancer with drugs
- **PAIN MEDICATIONS:** Easing pain with drugs
- **INVASIVE DIAGNOSTIC TESTS:** Inserting medical instruments into your body to identify problems (such as a biopsy)
- **ARTIFICIAL NUTRITION AND HYDRATION:** Providing food and water through a tube in the veins, nose or stomach
- **BLOOD OR BLOOD PRODUCTS:** Providing blood or parts of the blood (such as blood transfusions)
- **KIDNEY DIALYSIS:** Cleaning your blood by machine
- **MAJOR SURGERY:** Operating on vital organs (such as removing your appendix)
- **ORGAN TRANSPLANT:** Removing an unhealthy organ from your body and replacing it with a healthy organ from a donor
- **ARTIFICIAL RESPIRATION:** Breathing with mechanical or human assistance
- **CARDIOPULMONARY RESUSCITATION (CPR):** Using drugs and electric shock to restart your heart

## With whom should you discuss your Advance Directive?

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It is important to discuss your wishes with your family, friends, healthcare proxy, healthcare provider, as well as your lawyer and spiritual advisor. An Advance Directive expresses your decisions about life-sustaining treatment, but when your Advance Directive comes into effect, other people will be carrying out those wishes.

- **FAMILY:** Your immediate family members will be more comfortable to support your wishes if you have taken the time to discuss your wishes with them.
- **FRIENDS:** Friends are often thought of as extended family members, and for this reason you may wish to discuss your wishes with your friends.
- **HEALTHCARE PROXY:** If you have chosen a healthcare proxy or proxies, you should discuss your wishes with your proxy so that he, she or they can make decisions on your behalf that reflect your wishes.
- **LAWYER:** If you think that your wishes may not be observed, it may be important to discuss your Advance Directive with your lawyer. You may also wish to consult your lawyer about the proposed legislation in Alberta.
- **HEALTHCARE PROVIDERS:** Your healthcare providers will want to know that you are aware of the medical options available to you, and that your Advance Directive expresses your wishes. You should also discuss your instructions in detail with your doctor so that you know your wishes will be observed if medically and legally possible.
- **SPIRITUAL ADVISOR:** You may wish to discuss your Advance Directive with your spiritual advisor if you are concerned about your wishes conflicting with your faith.

## **Questions to ask your healthcare providers**

If it is important to you that your healthcare providers understands your feelings and wishes about life-sustaining treatments, you should discuss your Advance Directive with him or her when you are well.

Here are some questions you may wish to ask your doctor.

- If I was terminally ill with no hope of recovering, would you be willing to withdraw life-sustaining treatments?
- If I was terminally ill, would you object to giving me pain medications?
- If I was terminally ill, would you be concerned about my becoming addicted to pain medication?
- How do you feel about Advance Directives?

## **Questions to ask your lawyer**

Following are some questions you may wish to ask your lawyer.

- Is an Advance Directive legally binding in this province?
- Can anyone override my Advance Directive, or question my competency?
- How can I prove that I am competent?
- Will you acknowledge my competency to write this document?
- What if I change my mind?
- Can my family sue my doctor, or vice versa, if my wishes are not followed?

## **Can you change your mind?**

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Your beliefs about life and death may change over time. The wishes you express when you are well may not be the same as those when you are seriously ill.

You always have the right to revoke your Advance Directive when you are competent. To revoke your Advance Directive you may tear up the document or write REVOKED or CANCELLED on it. When you revoke your Advance Directive, make sure to destroy and replace ALL existing copies.

Under Bill 58, you may revoke your Advance Directive by writing a directive that is signed but not witnessed and that expresses your intention to revoke all or part of your Advance Directive. You may direct someone to destroy at least one signed copy of your Advance Directive, with the intention of revoking all signed copies. The proposed legislation also states that you may revoke your Advance Directive “(e) by giving oral instructions to revoke the directive if 2 or more persons who are at least 18 years of age are present and witness the instruction.”

### **When should you update your Advance Directive?**

If you change your mind, you should change your Living Will. You should review your Advance Directive on a regular basis, particularly when there are significant changes in your life. You should review your Advance Directive, for example, when you get married or you are admitted to hospital.



## **Where should you keep your Advance Directive?**

An Advance Directive speaks for you when you are no longer able to speak for yourself, so others must know that it exists. Once you have completed your Advance Directive, it is important that it be stored safely and that copies be given to your healthcare proxy (if you have appointed one), doctor, lawyer, family members and whomever is likely to be notified in an emergency. You will want these people to know that you have made an Advance Directive.

On each copy of your Advance Directive, you should indicate where other copies of your Advance Directive are located. Your completed Advance Directive should be filed with all your important personal documents. Many people use safety deposit boxes or a special file at home.

A copy of your Advance Directive should also be filed in your medical and hospital charts.



## Appendix A

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### **Summary: Things to consider when making your Advance Directive**

- Check the current laws in Alberta about Advance Directives and healthcare proxies.
- Express your instructions in writing.
- Indicate your instructions about life-sustaining treatments you do or do not want. (See page 11 for information about life-sustaining treatments)
- Sign and date your Advance Directive, and have it witnessed by two people. (See page 10 for information about who may act as your witness)
- Discuss your Advance Directive with those close to you, and give a copy to whomever is likely to be notified in an emergency.
- Give your doctor a copy of your Advance Directive to keep with your medical records.
- Give your lawyer a copy of your Advance Directive to keep on file.
- On each copy of your Advance Directive, you should indicate where other copies of your Advance Directive are located.
- Carry a card with you that states that you have an Advance Directive and where it can be found.
- Review your Advance Directive regularly.
- Inform your family, friends, healthcare proxy, healthcare providers, lawyer and spiritual advisor of any changes you make.
- Replace all copies of your Advance Directive if you make changes.
- Consult your healthcare providers or lawyer if you need more information.

## Appendix B

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### Glossary

**ADVANCE DIRECTIVE:** a written document where you indicate which life-sustaining treatments you want and do not want to have if you are seriously ill. An Advance Directive helps others make decisions for you if you are not able to do so yourself. Advance Directives are also called Living Wills, Advance Medical Directives, Healthcare Directives and Powers of Attorney for Personal Care

**APPROPRIATE DEATH:** the kind of death that you would want if you had a choice (See page 4)

**COMPETENT:** to be able to understand treatment choices and to understand their possible outcome

**DIRECTIVE:** the term used in an Advance Directive for the instructions or directions you prepare about healthcare decisions.

**HEALTHCARE PROXY:** the person you choose to make healthcare decisions for you when you are not able to (See page 2)

**INCOMPETENT:** to be unable to understand treatment choices and their possible outcome

**INSTRUCTION DIRECTIVE:** the part of an Advance Directive where you say which medical procedures you would or would not want in different situations (See page 2)

**INVASIVE DIAGNOSTIC TESTS:** the insertion medical instruments into the body to identify problems

**LAST WILL:** a document where you provide directions about what should happen with your estate and property when you die

**LIFE-SUSTAINING TREATMENTS:** an artificial or natural system that provides all or some of the items necessary for maintaining life such as oxygen, food, water (See page 11)

**LIVING WILL:** another name for an Advance Directive

NOTARY PUBLIC: a public officer who can certify documents to make them authentic

PERMANENT VEGETATIVE STATE: being in a physical or mental state where functioning is seriously impaired

PROXY DIRECTIVE: the part of an Advance Directive where you say who you want to make treatment decisions for you if you are no longer able to (See page 2)

REVOKE: to cancel (See page 13)

## **Appendix C**

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### **Government sources for information on Advance Directive legislation**

#### **FEDERAL**

Department of Justice  
Edmonton Regional Office  
Edmonton, Alberta

#### **PROVINCIAL**

Edmonton, Alberta

## Appendix D

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### Selected readings

Backer, Barbara A., editor

**Death and dying: Understanding and care**

2nd edition

Albany, New York: Delmar Publishers, Inc., 1994

Bommel, Harry van

**Choices: For people who have a terminal illness, their families and their caregivers**

Updated edition

Toronto: NC Press, 1993

Buchanan, Karin M.

**Coping when life is threatened**

Regina, Saskatchewan: Weigl Educational Publishers Ltd, 1984

Burnell, George M.

**Final choices: To live or to die in an age of medical technology**

New York: Plenum Press, 1993

Molloy, William, and Virginia Mephram.

**Let me decide: The health care directive that speaks for you when you can't.**

Toronto: Penguin Books Ltd., 1992

Rozovsky, Lorne Elkin, and Fay Adrienne Rozovsky

**The Canadian law of consent to treatment**

Toronto: Butterworth, 1990

## **Exclusion of liability and disclaimer**

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This package is designed to provide information about Advance Directives in Alberta for competent individuals who are 18 years of age and older. The form included in this package covers the most common situations, but it is difficult to provide for all circumstances. If what you want is not included in this package, please contact your lawyer or healthcare provider.

The information contained in this Advance Directive package has been carefully compiled. Its accuracy, however, is not guaranteed because laws and regulations may change or may be interpreted differently. The publisher, author and professional advisors who have approved the contents of this package shall not be liable for any loss or damage caused or alleged to be caused directly or indirectly by the information or any mistake contained in this Advance Directive package.

This Advance Directive package and other documents of this sort cannot replace a lawyer on important legal matters. If legal advice or other expert assistance is required, the services of a professional should be sought. It is recommended that a lawyer and a healthcare professional be consulted.

You should contact a lawyer or healthcare professional if you do not understand the instructions, if you are uncertain about how to complete and use the Advance Directive form, or if what you want to do is not precisely covered by the Advance Directive form provided.





